Association of Prognostic Estimates With Burdensome Interventions in Nursing Home Residents With Advanced Dementia

Loizeau, Andrea ; Shaffer, Michele L ; Habtemariam, Daniel A ; Hanson, Laura C ; Volandes, Angelo E ; Mitchell, Susan L

Abstract: Importance: Prognostication in advanced dementia is challenging but may influence care. Objectives: To determine the accuracy of proxies' prognostic estimates for nursing home residents with advanced dementia, identify factors associated with those estimates, and examine the association between their estimates and use of burdensome interventions. Design, Setting, and Participants: Data were combined from 2 studies that prospectively followed 764 residents with advanced dementia and their proxies in Boston-area nursing homes for 12 months: (1) the Study of Pathogen Resistance and Exposure to Antimicrobials in Dementia, conducted from September 2009 to November 2012 (362 resident/proxy dyads; 35 facilities); and (2) the Educational Video to Improve nursing home Care in End-Stage Dementia, conducted from March 2013 to July 2017 (402 resident/proxy dyads; 62 facilities). Proxies were the residents' formally or informally designated medical decision makers. Main Outcomes and Measures: During quarterly telephone interviews, proxies stated whether they believed the resident would live less than 1 month, 1 to 6 months, 7 to 12 months, or more than 12 months. Prognostic estimates were compared with resident survival. Resident and proxy characteristics associated with proxy prognostic estimates were determined. The association between prognostic estimates and whether residents experienced any of the following was determined: hospital transfers, parenteral therapy, tube feeding, venipunctures, and bladder catheterizations. Results: The residents' mean (SD) age was 86.6 (7.3) years; 631 (82.6%) were women and 133 (17.4%) were men. Of the 764 residents, 310 (40.6%) died later than 12 months. Proxies estimated survival with moderate accuracy (C statistic, 0.67). When proxies perceived the resident would die within 6 months, they were more likely to report being asked (183 [7.2%] of 2526) vs not being asked (126 [5.0%] of 2526) about goals of care by nursing home clinicians (adjusted odds ratio [AOR], 1.94; 95% CI, 1.50-2.52). Residents were less likely to experience burdensome interventions when the proxy prognostic estimate was less than 6 months (89 [4.4%] of 2031) vs greater than 6 months (1008 [49.6%] of 2031) (AOR, 0.46; 95% CI, 0.34-0.62). Conclusions and Relevance: Proxies estimated the prognosis of nursing home residents with advanced dementia with moderate accuracy. Having been asked about their opinion about the goal of care was associated with the proxies' perception that the resident had less than 6 months to live and that perception was associated with a lower likelihood the resident experienced burdensome interventions.

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Association of Prognostic Estimates With Burdensome Interventions in Nursing Home Residents With Advanced Dementia

Andrea J. Loizeau, MSc; Michele L. Shaffer, PhD; Daniel A. Habtemariam, BA; Laura C. Hanson, MD, MPH; Angelo E. Volandes, MD, MPH; Susan L. Mitchell, MD, MPH

IMPORTANCE Prognostication in advanced dementia is challenging but may influence care.

OBJECTIVES To determine the accuracy of proxies' prognostic estimates for nursing home residents with advanced dementia, identify factors associated with those estimates, and examine the association between their estimates and use of burdensome interventions.

DESIGN, SETTING, AND PARTICIPANTS Data were combined from 2 studies that prospectively followed 764 residents with advanced dementia and their proxies in Boston-area nursing homes for 12 months: (1) the Study of Pathogen Resistance and Exposure to Antimicrobials in Dementia, conducted from September 2009 to November 2012 (362 resident/proxy dyads; 35 facilities); and (2) the Educational Video to Improve nursing home Care in End-Stage Dementia, conducted from March 2013 to July 2017 (402 resident/proxy dyads; 62 facilities). Proxies were the residents' formally or informally designated medical decision makers.

MAIN OUTCOMES AND MEASURES During quarterly telephone interviews, proxies stated whether they believed the resident would live less than 1 month, 1 to 6 months, 7 to 12 months, or more than 12 months. Prognostic estimates were compared with resident survival. Resident and proxy characteristics associated with proxy prognostic estimates were determined. The association between prognostic estimates and whether residents experienced any of the following was determined: hospital transfers, parenteral therapy, tube feeding, venipunctures, and bladder catheterizations.

RESULTS The residents' mean (SD) age was 86.6 (7.3) years; 631 (82.6%) were women and 133 (17.4%) were men. Of the 764 residents, 310 (40.6%) died later than 12 months. Proxies estimated survival with moderate accuracy (*C* statistic, 0.67). When proxies perceived the resident would die within 6 months, they were more likely to report being asked (183 [7.2%] of 2526) vs not being asked (126 [5.0%] of 2526) about goals of care by nursing home clinicians (adjusted odds ratio [AOR], 1.94; 95% CI, 1.50-2.52). Residents were less likely to experience burdensome interventions when the proxy prognostic estimate was less than 6 months (89 [4.4%] of 2031) vs greater than 6 months (1008 [49.6%] of 2031) (AOR, 0.46; 95% CI, 0.34-0.62).

CONCLUSIONS AND RELEVANCE Proxies estimated the prognosis of nursing home residents with advanced dementia with moderate accuracy. Having been asked about their opinion about the goal of care was associated with the proxies' perception that the resident had less than 6 months to live and that perception was associated with a lower likelihood the resident experienced burdensome interventions.

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Supplemental content

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Author Affiliations: Hebrew SeniorLife Institute for Aging Research, Boston, Massachusetts (Loizeau, Habtemariam, Mitchell); University Research Priority Program, Dynamics of Healthy Aging, University of Zurich, Zurich, Switzerland (Loizeau); Department of Statistics, University of Washington, Seattle (Shaffer); Cecil G. Sheps Center for Health Services Research and School of Medicine, Division of Geriatric Medicine, University of North Carolina at Chapel Hill, Chapel Hill (Hanson); Department of Medicine, Massachusetts General Hospital, Boston (Volandes); Department of Medicine, Beth Israel Deaconess Medical Center, Boston, Massachusetts (Mitchell).

Corresponding author: Andrea J. Loizeau, MSc, Hebrew SeniorLife Institute for Aging Research, 1200 Centre St, Boston, MA 02131 (andrealoizeau@hsl.harvard.edu).

More than 5 million Americans have been diagnosed with Alzheimer disease, a number projected to increase to 13.8 million by 2050.[1] Alzheimer disease is the sixth most common cause of death in the United States.[2] Patients with advanced dementia commonly experience burdensome interventions that may be of limited benefit and do not promote comfort.[3-9]

Prognostication influences end-of-life care. The US Medicare Hospice benefit requires an estimated life expectancy of 6 months,[10] although the prognostic accuracy of hospice guidelines for dementia patients may be little better than chance.[11] Rigorously derived mortality risk scores for this population are only moderately accurate in predicting 6-month survival.[11-14] Nonetheless, prior work suggests that the perception of prognosis is an important driver of end-of-life care.[3,15-17] Our group found that nursing home residents with advanced dementia whose proxies perceived they had less than 6 months to live were less likely to get tube fed, hospitalized, or receive parenteral therapy in their last 180 days of life.[3] However, this retrospective analysis was limited to a small decedent cohort and did not examine factors influencing prognostic perceptions. Proxies of patients with advanced cancer and critical illness report basing their prognostic perceptions on factors such as the need to remain hopeful, religious beliefs, and patient attributes (ie, fortitude).[18-20]

To better understand proxies' perceptions of prognosis and their role in the care of nursing home residents with advanced dementia, we combined data from 2 studies conducted by our group: the Study of Pathogen Resistance and Exposure to Antimicrobials in Dementia (SPREAD)[9,21]; and the Educational Video to Improve Nursing Home Care in End-Stage Dementia (EVINCE) trial.[22] In both studies, proxies of nursing home residents with advanced dementia were prospectively asked every 3 months (up to 12 months) how long they felt the resident had to live. The objectives were to (1) determine the accuracy of proxies' prognostic estimates, (2) identify factors associated with their prognostic estimates, and (3) examine the association between proxies' perceived prognosis and the residents' receipt of potentially burdensome interventions.

Key Points

Question How do proxies perceive the prognosis of nursing home residents with advanced dementia and how do their perceptions influence care?

Findings In this combined analysis of 2 studies, proxies estimated the prognosis of residents with advanced dementia (764 dyads) with moderate accuracy. Residents whose proxies perceived a prognosis shorter than 6 months were significantly less likely to experience burdensome interventions.

Meaning Proxies are reasonably good at estimating when residents with advanced dementia will die, and their prognostic perceptions may influence the type of care that residents receive.

Methods

Data Sources

Data were leveraged from 2 studies with identically defined populations and data collection methods for the variables used in this study: (1) SPREAD[9,21]; and (2) EVINCE.[22] The SPREAD study was a prospective cohort study conducted from September 2009 through November 2012 in which 362 nursing home residents with advanced dementia were followed in 35 Boston-area facilities for 12 months to describe infection management. The EVINCE Study was a cluster randomized clinical trial conducted in 62 Boston-area facilities (intervention, n = 31; control, n = 31) conducted from March 2013 to July 2017. Proxies of nursing home residents with advanced dementia in 212 intervention facilities were exposed to an advance care planning video, whereas those in the 190 control facilities experienced usual care. Residents were followed for 12 months. Observational data from the intervention and control arms were combined for this study.

Hebrew SeniorLife institutional review board approved the conduct of both studies. Proxies provided informed consent for the residents' and their own participation. They were not compensated.

Study Population

Recruitment procedures were the same in both studies. Resident eligibility criteria included (1) age 65 years or older, (2) dementia (any type), (3) Global Deterioration Scale (GDS) score of 7 (from nurse; range, 1-7; higher scores indicate worse dementia),[23] (4) available English-speaking proxy, and (5) nursing home stay longer than 90 days. A GDS score of 7 is characterized by profound memory deficits (cannot recognize family), verbal ability of less than 5 words, incontinence, and nonambulatory status. Every 3 months, research assistants (RAs) asked nurses on each nursing home unit to identify eligible residents. Dementia diagnosis, age, and proxy availability were confirmed by medical record review. Proxies were the residents' formally or informally designated medical decision makers.

Data Elements

All variables were collected and defined similarly in both studies, unless otherwise stated. Residents' medical records were abstracted, and proxies were interviewed by RAs at baseline and quarterly thereafter for up to 12 months. If the resident died, the medical record was reviewed within 14 days of death. Proxy interviews were conducted by telephone except for in-person baseline interviews in EVINCE.

This study focused on the following question asked at all proxy interviews: "In your opinion, how close do you feel [resident] is to the end of her/his life?" with the following response options: (1) less than 1 month, (2) 1 to 6 months, (3) 7 to 12 months, (4) longer than 12 months, and (5) do not know or refused.

Two other outcomes were examined: death and use of burdensome interventions. The RAs contacted nursing units bimonthly to determine if any residents had died and if so the date of death. At each assessment, the following potentially burdensome interventions experienced by residents since the

prior assessment were abstracted from their medical records: hospital transfers (hospitalizations or emergency department visits), parenteral therapy for hydration or medication administration, new feeding tube insertion, venipunctures, and bladder catheterizations to work-up suspected urinary tract infections (only available in SPREAD). We selected these interventions because they were potential sources of discomfort in frail older persons,[24] and generally do not reflect comfort-focused care.

Other variables were used to describe residents and proxies and were included as covariates.[3,15-20] Baseline resident data included demographics (age, sex, and race [white vs other], etiology of dementia [Alzheimer disease vs other], common comorbidities [chronic obstructive pulmonary disease, congestive heart failure, and diabetes], Test for Severe Impairment [TSI] score obtained by direct resident examination [range, 0-24; lower scores indicate greater cognitive impairment; dichotomized to equal to vs greater than 0],[25] and functional status by nurse interview using the Bedford Alzheimer Nursing Severity-Subscale [BANS-S; range, 7-28; higher scores indicate greater functional disability]).[26] At every assessment, it was determined whether the resident experienced any of the following new major illnesses since the prior assessment: hip fracture, stroke, myocardial infarction, major gastrointestinal bleed, pneumonia, and new diagnosis of cancer (other than localized skin cancer).

Baseline proxy data included age, sex, years as proxy, and relationship to resident (child vs other). At all interviews, proxies were asked whether any nursing home clinicians had asked their opinion about the resident's goal of care (yes/no).

Analysis

Analyses were conducted using SAS statistical software (version 9.4, SAS Institute). Main results were generated for the combined cohorts and presented for each study separately in eTable 1, eTable 2, and eTable 3 in the Supplement. Means (SDs), and frequencies were used to describe continuous and categorical variables, respectively.

Cumulative incidence of death was displayed graphically and compared between SPREAD and EVINCE using survival analysis. For residents who died, survival time was calculated as the number of days between the date of baseline proxy interview and date of resident death. For all analyses examining survival as an outcome, residents who survived the follow-up period were censored at 12 months and those lost to follow-up were censored at the last known follow-up date.

Cox proportional hazards regression examined the accuracy of proxies' prognostic estimates (independent variable) as ascertained from all interviews and analyzed as time-varying variables. A prognostic estimate later than 12 months was the referent category. The model examined the association between the prognostic estimates at a particular interview date and the risk of the resident dying given that the resident had survived up until that point. Because response options did not include prognostic estimates between 6 and 7 months, actual survival times during that interval were rounded up or down. Robust standard errors accounted for clustering at the facility level. Adjusted hazard ratios (AHRs) and 95% confidence intervals (CIs) were computed. A generalized version of the *C* statistic allowing for censored data was calculated as a measure of the model's overall accuracy (range, 0.5-1; higher scores indicate greater accuracy).[27] A sensitivity analysis excluded proxies in the EVINCE intervention group because the video could have influenced the accuracy of their prognostic estimates.

Logistic regression was used to identify resident and proxy characteristics (independent variables) associated with a proxy prognostic estimate of less than 6 months (outcome). The prognosis variable was dichotomized because the proportion of interviews at which proxies estimated prognosis to be less than 1 month and 1 to 6 months were too small to examine as separate categories. Interviews at which the proxy responded "do not know" or refused to answer were excluded. The analysis was conducted at the level of assessment intervals. Independent variables considered a priori to be possibly associated with prognostication[3,18-20] included resident demographics (age [dichotomized at median], sex, race), dementia type, comorbidities, TSI, BANS-S, hospital transfer in prior 3 months, proxy demographics (age [dichotomized at median], sex), proxy relationship to resident, and goals of care discussions. Proxy prognostic estimates and other dynamic independent variables (eg, hospital transfers) were ascertained from each assessment. Static variables (eg, sex) were brought forward from baseline. Bivariable analyses examined the unadjusted associations between each independent variable and prognosis at a given assessment interval. Variables associated with the outcome at $P < .10$ in the unadjusted analyses were entered into a multivariable model. Generalized estimating equations (GEE) accounted for clustering among resident/proxy dyads. Odds ratios (ORs) with 95% CIs were computed.

Finally, logistic regression was used to examine the association between a proxy prognostic estimate of less than 6 months (main independent variable) and the use of any of the following burdensome interventions (outcome): hospital transfer, parenteral therapy, new feeding tube, venipuncture, and bladder catheterization. The analysis was conducted at the level of assessment intervals and excluded assessments with "do not know/refused" responses to the prognosis question. Prognosis was derived from the interview conducted at the beginning of a given 3-month interval. The outcome was defined as whether the resident experienced a burdensome intervention during the 3-month interval following that interview. Covariates considered a priori to be possibly associated with intervention use[3,15-17] included: resident demographics, dementia type, comorbidities, TSI, BANS-S, new major illness, proxy demographics, proxy relationship to resident, and goals of care discussions. Dynamic covariates were drawn from the assessment that best related the resident's status during the interval. For example, occurrence of a major illness was ascertained from the medical record review done at the end of the interval, which recorded events during the interval. Being asked about goals of care was drawn from the interview at the start of the interval. Static variables were brought forward from baseline. Bivariable followed by multivariable analyses were conducted as described herein, and GEE accounted for clus-

Table 1. Baseline Characteristics of Nursing Home Residents With Advanced Dementia and Their Proxies

Characteristics	No. (%) SPREAD and EVINCE Combined (n = 764)	SPREAD (n = 362)	EVINCE (n = 402)
Resident			
Age, mean (SD), y	86.6 (7.3)	86.5 (7.3)	86.7 (7.4)
Age >87 y (median)	362 (47.4)	174 (48.1)	188 (46.8)
Female	631 (82.6)	308 (85.1)	323 (80.3)
White (vs other)	685 (89.7)	335 (92.5)	350 (87.1)
Alzheimer disease (vs other)	552 (72.3)	269 (74.3)	283 (70.4)
Chronic obstructive pulmonary disease	90 (11.8)	42 (11.6)	48 (11.9)
Congestive heart failure	120 (15.7)	63 (17.4)	57 (14.2)
Diabetes	146 (19.1)	67 (18.5)	79 (19.7)
TSI = 0 (vs greater than 0)	412 (53.9)	222 (61.3)	190 (47.3)
BANS-S, mean (SD)	20.6 (2.8)	21.2 (2.7)	20.1 (2.8)
BANS-S >21 (median)	328 (42.9)	182 (50.3)	146 (36.3)
Enrolled in hospice	105 (13.7)	31 (8.6)	74 (18.4)
Died during 12-mo follow-up	310 (40.6)	135 (37.3)	175 (43.5)
Proxy			
Age, mean (SD)[a]	61.4 (10.6)	60.4 (10.3)	62.3 (10.8)
Age >61 y (median)	348 (45.6)	153 (42.3)	195 (48.5)
Female	492 (64.4)	226 (62.4)	266 (66.2)
Years as proxy, mean (SD)[a]	8.8 (6.3)	8.1 (5.7)	9.4 (6.8)
Child of resident (vs other)	489 (64.0)	233 (64.4)	256 (63.7)
Prognostic estimates of resident survival at the baseline interviews only			
<1 mo	10 (1.3)	3 (0.8)	7 (1.7)
1-6 mo	75 (9.8)	29 (8.0)	46 (11.4)
7-12 mo	148 (19.4)	59 (16.3)	89 (22.1)
>12 mo	477 (62.4)	240 (66.3)	237 (59.0)
Don't know or refused to answer	54 (7.1)	31 (8.6)	23 (5.7)

Abbreviations: BANS-S, Bedford Alzheimer's Nursing Severity-Subscale (range, 7-28; higher scores indicate more functional disability); EVINCE, the Educational Video to Improve Nursing Home Care in End-Stage Dementia; SPREAD, the Study of Pathogen Resistance and Exposure to Antimicrobials in Dementia; TSI, Test for Severe Impairment (range, 0-24; lower scores indicate greater cognitive impairment).

[a] Data missing for proxy age (n = 10) and years as proxy (n = 5).

tering among resident/proxy dyads. Odds ratios with 95% CIs were computed.

Results

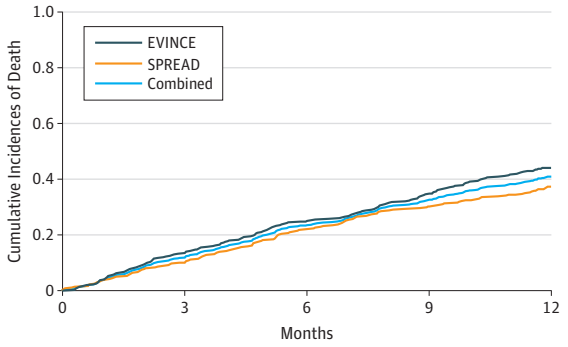
Resident and Proxy Characteristics

Baseline characteristics were comparable between the 2 studies (SPREAD, 362 dyads; EVINCE, 402 dyads) (**Table 1**). Resident characteristics of the combined cohort (764 dyads) included mean (SD) age, 86.6 (7.3) years; female, 631 (82.6%); and white, 685 (89.7%). A total of 412 residents (53.9%) had TSI scores equal to 0, and their mean (SD) BANS-S score was 20.6 (2.8), indicating severe cognitive and functional impairment, respectively. Proxy characteristics were mean (SD) age, 61.4 (10.6) years; female, 492 (64.4%); mean (SD) years as a proxy, 8.8 (6.3); and child of a resident, 489 (64.0%).

Survival and Accuracy of Proxy Prognostic Estimates

In the combined cohort, 310 (40.6%) residents died, and 11 (1.4%) were lost to follow-up. In SPREAD, 135 (37.3%) residents died and 5 (1.4%) were lost to follow-up. In EVINCE, 175

Figure. Cumulative Incidences of Death Among 764 Nursing Home Residents With Advanced Dementia



No. at risk

EVINCE	402	341	295	243	221
SPREAD	362	317	274	241	222
Combined	764	658	569	484	434

Cumulative incidences of death among nursing home residents with advanced dementia in the Study of Pathogen Resistance and Exposure to Antimicrobials in Dementia (SPREAD) study (n = 362) and the Educational Video to Improve Nursing Home Care in End-Stage Dementia (EVINCE) study (n = 402), and the 2 studies combined (n = 764).

Table 2. Association Between Characteristics of Nursing Home Residents With Advanced Dementia and Their Proxies and the Proxy's Perception That the Resident Had Less Than 6 Months to Live[a]

Characteristic	Assessment Intervals With Characteristic[a] (n = 2526), No. (%)	Assessment Intervals in Which Proxy Estimated Resident Had <6 Months to Live (n = 309), No. (%)		Unadjusted Odds Ratio[b] for Proxy-Perceived Prognosis (95% CI)
		With Characteristic Present	With Characteristic Absent	
Resident				
Age >87 y (median)	1178 (46.6)	164 (6.5)	145 (5.7)	1.34 (0.96-1.88)[c]
Female	2110 (83.5)	248 (9.8)	61 (2.4)	0.78 (0.50-1.21)
White	2272 (89.9)	279 (11.1)	30 (1.2)	1.05 (0.56-1.96)
Alzheimer disease	1813 (71.8)	216 (8.6)	93 (3.7)	0.90 (0.62-1.31)
Chronic obstructive pulmonary disease	264 (10.5)	43 (1.7)	266 (10.5)	1.46 (0.92-2.32)
Congestive heart failure	387 (15.3)	52 (2.1)	257 (10.2)	1.14 (0.71-1.81)
Diabetes	454 (18.0)	56 (2.2)	253 (10.0)	1.01 (0.66-1.56)
TSI = 0	1315 (52.1)	165 (6.5)	144 (5.7)	1.06 (0.76-1.49)
BANS-S >21 (median)	996 (39.4)	129 (5.1)	180 (7.1)	1.12 (0.80-1.56)
Any hospital transfer in prior 3 mo[d]	100 (4.0)	17 (0.7)	292 (11.6)	1.50 (0.86-2.60)
Proxy				
Age >61 y (median)[e]	1186 (47.4)	158 (6.3)	149 (6.0)	1.20 (0.86-1.69)
Female	1613 (63.9)	224 (8.9)	85 (3.4)	1.57 (1.10-2.24)[c,f]
Child of resident	1565 (62.0)	200 (7.9)	109 (4.3)	1.15 (0.80-1.65)
Asked their opinion about goals of care by a nursing home clinician	1126 (44.6)	183 (7.2)	126 (5.0)	1.96 (1.52-2.54)[c,g]

Abbreviations: BANS-S, Bedford Alzheimer Nursing Severity-Subscale (range, 7-28; higher scores indicate greater functional disability); TSI, Test for Severe Impairment (range, 0-24; lower scores indicate greater cognitive impairment).

[a] Analyses were done at the level of assessment intervals, which included all baseline and follow-up resident/proxy assessment intervals (n = 2526). Resident medical chart reviews and proxy interviews were done at baseline and quarterly for up to 12 months. Static variables were brought forward from baseline. Proxy's perception of prognosis and other dynamic variables (eg, goals of care discussion, hospital transfers) were ascertained from each assessment period. Proxies stated the resident had less than 6 months to live at 12.2% of all baseline and follow-up assessment intervals (309 of 2526).

[b] Unadjusted and adjusted odds ratio accounted for clustering among resident/proxy dyads using generalized estimating equations.

[c] Variables that were significant at $P < .10$ in bivariable analyses and entered into the multivariable model.

[d] Hospital transfer included hospitalization or emergency department visit.

[e] Age missing for 24 proxies.

[f] Adjusted odds ratio, 1.55 (95% CI, 1.09-2.20).

[g] Adjusted odds ratio, 1.94 (95% CI, 1.50-2.52).

(43.5%) residents died and 6 (1.5%) were lost to follow-up. Six-month mortality rates were: combined cohort, 195 (25.5%); SPREAD, 88 (24.3%); and EVINCE, 107 (26.6%). The **Figure** shows the cumulative incidences of death for the combined cohort and each cohort separately, which did not differ significantly (log rank $P = .08$).

At baseline, proxies' estimates of the resident prognosis were: less than 1 month, 10 (1.3%); 1 to 6 months, 75 (9.8%); 7 to 12 months, 148 (19.4%); longer than 12 months, 477 (62.4%); and do not know/refused, 54 (7.1%). At all 2649 proxy interviews (ie, baseline and follow-up), proxy prognostic estimates were: less than 1 month, 30 (1.1%); 1 to 6 months, 279 (10.5%); 7 to 12 months, 664 (25.1%); over 12 months, 1553 (58.6%); and do not know/refused, 123 (4.6%). In the Cox model, the likelihood of dying was higher among residents whose proxies thought they had a shorter prognosis (referent, longer than 12 months): less than 1 month (AHR, 27.53; 95% CI, 15.81-47.95); 1 to 6 months (AHR, 4.61; 95% CI, 3.12-6.79); 7 to 12 months (AHR, 1.91; 95% CI, 1.38-2.64); and do not know/refused (AHR, 0.92; 95% CI, 0.40-2.14). The model's *c* statistic was 0.67. Results were similar when analyzed in the EVINCE cohort with the intervention arm excluded: less than 1 month (AHR, 28.77; 95% CI, 13.99-59.18); 1 to 6 months (AHR, 4.89; 95% CI, 3.10-7.71); 7 to 12 months (AHR, 2.05; 95% CI, 1.43-2.94); and do not know/refused (AHR, 1.04; 95% CI, 0.39-2.78). The *C* statistic was 0.67.

Factors Associated With Proxy Prognostication

The proportion of all interviews (2526) at which proxies stated that the resident had less than 6 months was 12.2% (309). In unadjusted analyses, variables associated with a proxy prognostic estimate of less than 6 months at a $P < .10$ were resident age older than 87 years, female proxy, and being asked about goals of care (**Table 2**). In the multivariable model, only having been asked about goals of care (AOR, 1.94; 95% CI, 1.50-2.52) and female proxy (AOR, 1.55; 95% CI, 1.09-2.20) remained significantly associated with a prognostic estimate of less than 6 months.

Use of Burdensome Interventions

There were 2031 resident-assessment intervals available to examine the use of burdensome interventions over the

Table 3. Association Between Proxy Perception of Prognosis and Use of Burdensome Interventions Among Nursing Home Residents With Advanced Dementia[a]

Characteristic	Assessment Intervals With Characteristic[b] (n = 2031), No. (%)	Assessment Intervals in Which Resident Had Any Burdensome Interventions (n = 1097), No. (%)		Likelihood of a Burdensome Intervention OR[c] (95% CI)	
		With Characteristic Present	With Characteristic Absent	Unadjusted	Adjusted
Proxy estimated resident had <6 mo to live	251 (12.4)	89 (4.4)	1008 (49.6)	0.47 (0.35-0.62)[d]	0.46 (0.34-0.62)
Resident covariates					
Age >87 y (median)	954 (47.0)	490 (24.1)	607 (29.9)	0.81 (0.64-1.02)[d]	0.77 (0.61-0.97)
Female	1691 (83.3)	917 (45.2)	180 (8.9)	1.13 (0.83-1.52)	
White	1837 (90.5)	970 (47.8)	127 (6.3)	0.58 (0.40-0.86)[d]	
Alzheimer disease	1472 (72.5)	781 (38.5)	316 (15.6)	0.89 (0.69-1.14)	
Chronic obstructive pulmonary disease	217 (10.7)	120 (5.9)	977 (48.1)	1.00 (0.69-1.44)	
Congestive heart failure	318 (15.7)	203 (10.0)	894 (44.0)	1.63 (1.19-2.22)[d]	1.63 (1.19-2.24)
Diabetes	357 (17.6)	243 (12.0)	854 (42.1)	1.94 (1.41-2.67)[d]	1.91 (1.39-2.63)
TSI = 0	1053 (51.9)	501 (24.7)	596 (29.4)	0.57 (0.46-0.72)[d]	0.66 (0.52-0.86)
BANS-S >21 (median)	808 (39.8)	373 (18.4)	724 (35.7)	0.58 (0.46-0.74)[d]	0.68 (0.53-0.88)
Any new major illness in prior 3 mo[e]	109 (5.4)	82 (4.0)	1015 (50.0)	2.59 (1.70-3.96)[d]	2.83 (1.84-4.35)
Proxy covariates					
Age >61 y (median)[f]	941 (46.3)	481 (23.7)	606 (29.8)	0.78 (0.62-0.98)[d]	
Female	1288 (63.4)	671 (33.0)	426 (21.0)	0.86 (0.68-1.08)	
Child of resident	1268 (62.4)	709 (34.9)	388 (19.1)	1.22 (0.97-1.55)[d]	
Asked their opinion about goals of care by a nursing home clinician	953 (46.9)	501 (24.7)	596 (29.4)	0.88 (0.74-1.04)	

Abbreviations: BANS-S, Bedford Alzheimer Nursing Severity-Subscale (range, 7-28; higher scores indicate more disability); OR, odds ratio; TSI, Test for Severe Impairment (range, 0-24; lower scores indicate greater cognitive impairment).

[a] Burdensome interventions included any of the following: hospital transfer (hospitalization or emergency department visits), parenteral therapy, new feeding tube insertion, venipuncture, and bladder catheterizations.

[b] Analyses were done at the level of assessment intervals, which included baseline and follow-up resident/proxy assessment intervals (n = 2031). Proxy prognosis was taken from the interview done at the start of the interval. The use of burdensome interventions reflected the resident's experience during the 3-month interval following that interview. Dynamic covariates were drawn from the assessment that best reflected the resident's status during the interval of interest (eg, any new major illness). Static variables were brought forward from baseline.

[c] Unadjusted and adjusted OR accounted for clustering among resident/proxy dyads using generalized estimating equations.

[d] Variables that were significant at $P < .10$ in bivariable analyses and entered into the multivariable model.

[e] Any new major illness included hip fracture, stroke, myocardial infarction, major gastrointestinal bleed, pneumonia, and/or new diagnosis of cancer (other than localized skin cancer).

[f] Age missing for 18 proxies.

follow-up period. The proportion of intervals during which residents experienced burdensome interventions were: hospital transfer, 68 (3.3%); parenteral therapy, 49 (2.4%); new feeding tube, 3 (0.1%); venipuncture, 1048 (51.6%); bladder catheterizations, 157 (7.7%); and any intervention, 1097 (54.0%). In unadjusted analyses, factors associated with a lower likelihood of any burdensome intervention use at $P < .10$ included: proxy prognosis of less than 6 months, resident age older than 87 years, white resident, TSI equal to 0, BANS-S greater than 21, proxy age older than 61 years, and child of resident (**Table 3**). Congestive heart failure, diabetes, and any new major illness were associated with a greater likelihood of receiving a burdensome intervention. After multivariable adjustment, a prognostic estimate of less than 6 months remained significantly associated with a lower likelihood of the resident receiving any burdensome interventions (AOR, 0.46; 95% CI, 0.34-0.62).

Discussion

In this study, proxies of nursing home residents with advanced dementia predicted how long the resident would live with moderate accuracy. Having been asked about their opinion about the goals of care was the factor most strongly associated with the proxies' perception that the resident had less than 6 months to live. Residents were significantly less likely to experience burdensome interventions when their proxies perceived they would die within 6 months.

The accuracy of the proxy's prognostic estimates was modest, but remarkably identical to the empirically derived Advanced Dementia Prognostic Tool (*c* statistic, 0.67), and better than hospice guidelines for dementia (*c* statistic, 0.55).[11] Prognostic estimates of proxies of patients in intensive care units are reportedly somewhat more accurate (*c* statistic,

0.74),[18] perhapsbecause it is easier to recognize impending death in the context of critical illness. We found that most proxies believed the resident would die within 6 months, and that they underestimated mortality; 310 (40.6%) of residents died after 12 months but at baseline only 233 (30.5%) of proxies perceived the resident would die in 12 months. An overly optimistic perception of prognosis is a consistent finding among proxies, patients, and clinicians in the context of other serious illnesses.[15,18,28,29]

Having been asked their opinion about the goals of care by nursing home clinicians was most strongly associated with proxies' perception that the resident had less than 6 months to live. Given that the question referred to a time period before the proxy interview, renders it less likely the association was owing to proxies seeking out goals of care discussions as a consequence of believing the resident may die soon. Although we did not ascertain the contents of these conversations, research from the critical care setting found that clinicians make prognostic statements of some nature in most discussions about goals of care.[30]

This study supports and furthers research suggesting that patients whose proxies believe they are close to the end of life are more likely to opt for comfort-focused care,[22] and receive fewer burdensome interventions.[3,15-17] A cross-sectional analysis of baseline EVINCE data found that proxies who perceived that the resident had a life expectancy of less than 6 months were significantly more likely to prefer a level of care that only included treatments to reduce suffering versus one that included potentially life-prolonging but uncomfortable interventions (AOR, 12.25; 95% CI, 4.04-37.08).[22] The interventions considered potentially burdensome in this study are not indicative of comfort-focused care. Even venipunctures and bladder catheterizations, which may be considered relatively benign, can be a source of discomfort in these very frail residents and generally are not undertaken when the goal of care is solely comfort.[24]

Limitations

Several limitations of this study deserve comment. First, the study was limited to a primarily white cohort in Boston-area nursing homes, and thus findings may not be generalizable to other regions or populations. Second, proxies selected their prognostic estimates from categories of expected survival. Alternative approaches, such as estimating the probability of surviving a given time frame (probability approach), asking about life expectancy in a more open-ended fashion (temporal approach), or the "surprise question" method, may yield different prognostic accuracies.[29,31,32] Third, we could not assess the accuracy of the proxies' reports about being asked about goals of care or which aspects of these discussions may have influenced their prognostic estimates. It is likely that factors not captured in the data set impacted those perceptions,[18-20] but require a qualitative approach to elucidate.

Conclusions

This study demonstrates that proxies are moderately accurate in estimating how long nursing home residents with advanced dementia will live. Regardless of accuracy, the proxy's perception that the resident may die within 6 months was associated with the use of fewer burdensome interventions. Goals of care discussions with clinicians may be important for proxies to gain that perception. In advanced dementia, in which highly accurate prognostication can be elusive, an understanding of the terminal nature of this condition may be pertinent to promoting a comfort-focused approach to care.

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Concept and design: Loizeau, Shaffer, Hanson, Volandes, Mitchell.
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Drafting of the manuscript: Loizeau, Mitchell.
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